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Challenging the Biopsychosocial Model in a Chronic Constipation Clinic

Megan Wainwright¹, Andrew J. Russell¹ and Yan Yiannakou²

¹ Durham University, Durham, United Kingdom

² County Durham and Darlington NHS Foundation Trust, United Kingdom

Corresponding Author:

Megan Wainwright, Durham University, Medical Anthropology Research Group, Department of Anthropology, Dawson Building, South Road, Durham, DH1 3LE.

Email: megan@meganwainwright.ca

Abstract

In this article we discuss the results of an ethnographic study of professionals' and patients' experiences within a specialist constipation clinic in England. Chronic constipation tends to be poorly understood and inadequately treated. Eleven patients were followed through their illness trajectory during a 5-month field work period, involving 21 home interviews, clinic-based interviews, participant-observation, and a focus group. Professionals were likewise observed and interviewed. The clinic could broadly be described as biopsychosocial in its approach. However, professionals expressed uncertainty about how best to provide biopsychosocial care and suggested that some patients were not "open" to psycho-social therapies or to discussing psycho-social aspects of their disease. Patients' concerns were with being taken seriously, receiving treatment and narrating intersections of life events, emotional well-being and the bowels. We situate these findings within the discourse of "functional" disorders and discuss why implementing a biopsychosocial approach is problematic in this case.

Keywords

anthropology; ethnography; health care professionals; health care, users' experiences; illness and disease, chronic; narrative inquiry; observation, participant; pain, chronic; relationships, health care; sensitive topics

Constipation is normally an isolated, discrete experience of delayed bowel movement, straining during defecation, the eventual passing of hard and small stool, and a sense of incomplete evacuation. It is a very common condition (Drossman, 1994). However, for some people constipation is experienced as a chronic illness characterized by abdominal pain, bloating, and poor health perception (Dubois, Johnson, Marquis, & McGrath, 1997). In the literature, this is known as functional constipation, referred to synonymously as chronic constipation, idiopathic constipation, or constipation-predominant irritable bowel syndrome (IBS). Although not all IBS involves constipation, the literature on IBS presented here includes constipation-predominant IBS.

Medicine has made creditable strides in prolonging life and enhancing the quality of life for people with a number of chronic diseases. However, “functional” diseases are a class of health conditions about which western biomedicine generally has little understanding and even fewer answers. These diseases cause significant suffering, yet routine investigatory tests do not detect any pathological cause. They have therefore come to be a category of exclusion existing in almost every medical specialty (e.g. functional paralysis or functional arthritis). Other commonly applied terms to designate functional disease are “idiopathic”, “ambiguous chronic illness” (Johnson & Johnson, 2006) or even “medically unexplained physical symptoms” (MUPS) (Burton, 2003). Functional constipation belongs to the category of functional gastrointestinal disorders (FGIDs). It is defined as “infrequent or incomplete defecation not caused by medication, or specific medical or psychiatric disease” (Drossman, 1994, p. 11). In other words, it is a condition which occurs without any “definable dietary, systemic or local structural cause” (Lennard-Jones, 1994, p. 7). Essentially the organ/structure (in this case, the bowel) is not functioning as it should but the reason why is not clear.

It is a short shift, biomedically speaking, from saying the cause of a disorder or the pathological explanation for its symptoms is unknown to assuming that the problem is psychosomatic or all “in people’s heads.” For many physicians, a FGID is a “psychological disorder or the absence of organic disease” which, in some cases, involves “pejorative features toward the patient” (Drossman, 2005, p. 1772). Research has not, however, explored what patients understand by the medical labeling of their illness as “functional”. Clinician-researchers such as Drossman have demonstrated that these disorders are not simply “in people’s heads” but are the real manifestations of a complex interaction of the biological, social, and psychological (Gwee et al., 1999; Lackner et al., 2010; Wald, Hinds, & Caruana, 1989). Drossman claimed that this view is becoming more acceptable in medicine because of three interacting developments: (a) the increasing support of the biopsychosocial model of illness and disease; (b) innovation in investigatory methods for studying disease; (c) the development of the Rome Criteria for classifying FGIDs (Drossman & Swankowski, 2010). The Rome criteria are an attempt to standardize diagnosis of conditions which have no confirmatory tests and are defined by wide-ranging symptoms. Combinations of symptoms, occurring in association with physiological functions, and over certain periods of time, can be used to classify these disorders with a variable degree of accuracy (Drossman et al., 2006). Because patients in this study did not use the term “functional” and because of the persistent troublesome associations that the term “functional” has in biomedicine, we use the term “chronic constipation” in this article.

Illness Experience and Health Care Relationships: Constipation in Historical and Cultural Perspective

Constipation is a common human experience. Western peoples and biomedical practitioners have been particularly concerned with the functioning of the bowels. Indeed, FGIDs represent a major

proportion of the complaints dealt with in primary care and are the most commonly seen conditions in gastroenterology clinics (Drossman, 1999; Talley, 2008). Historically, Western peoples have seen regular bowel movements as symbolic of a well-functioning system, with their disruption considered a risk factor for graver illness (Wharton, 2000). Autointoxication, the 19th century idea that waste retained because of constipation would cause self-poisoning (Wharton, 2000), is a theory that has persisted in 20th century medical anthropology in the form of “Burkitt’s Hypothesis” (Burkitt, 1978).

For Drossman and Swantkowski (2010), the key to good health care for FGID patients lies with a provider-patient relationship characterized by active listening, decision making that involves the patient, and a patient-centered care plan that is biopsychosocial in its approach. However, research into patients’ perspectives of living with FGIDs suggests that patient-health care provider relationships continue to be fraught with difficulty. Hakanson, Sahlberg-Blom, and Ternstedt (2010) discussed how nine IBS patients from a gastroenterology outpatient clinic experienced their encounters with health care professionals as either supportive or unsupportive. The latter were more prominent and were characterized by humiliation, a sense of insignificance, and abandonment. Dhaliwal and Hunt’s (2004) literature review on the effect of an IBS diagnosis on the interactions between patients and physicians concluded that

Disparity seems to lie with the physician, who needs to provide more trust, knowledge, and sympathy, create rapport and be forthcoming with information, while keeping information simple and understandable. Patient dissatisfaction stems from the actual information provided and how this is communicated (p. 1161).

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3 Information about causes and treatment remains very limited. For this reason, health care
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5 providers, particularly physicians, might feel insecure in their ability to manage these patients,
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7 sometimes leading them to avoiding sufferers altogether (Drossman, 1999).
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10 In their interviews with doctors and patients regarding their perceptions of IBS, Dixon-
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12 Wood and Critchley (2000) found that general practitioners and gastroenterologists considered
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14 IBS an unrewarding disease to treat. This was because of medicine's poor understanding of the
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16 disease, lack of effective treatments, and perceived difficulties of dealing with IBS patients
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18 whom doctors readily categorized as either "good" or "bad". Doctors described "bad" IBS
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20 patients as difficult to talk to, never finding treatments helpful, and demanding of expensive and
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22 lengthy investigations. "Dissatisfied patients felt that doctors trivialized their symptoms, saw IBS
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24 as a 'dustbin diagnosis', did not offer them enough time and failed to recognize the impact of the
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26 symptoms on their quality of life" (p. 111). Patients reported feeling deeply stigmatized and let
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28 down by medicine, their fears ridiculed and their symptoms trivialized.
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34 Although chronic constipation, like other FGIDs, might not be immediately life-
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36 threatening, research has argued it significantly affects a person's quality of life (Belsey,
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38 Greenfield, Candy, & Geraint, 2010). However, despite the considerable suffering chronic
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40 constipation can cause (a characteristic reflected in the research to be reported here), it tends not
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42 to figure within national health frameworks and has attracted relatively little research interest
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44 (Mihaylov et al., 2008). This in turn perpetuates the limited knowledge and understanding of the
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46 disorder and how to treat it. Unclear information and unhelpful treatment suggestions can be
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48 frustrating for patients who have come to expect a certain kind of efficacy from biomedical,
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50 cure-focused care. Annells and Koch (2003) reported that elderly people suffering from
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52 constipation found that having recommendations for proper diet, fluid intake and exercise
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continuously preached to them by nurses was frustrating, especially when they achieved minimal success. The authors concluded that, according to the scientific and medical literature, “evidence...for dietary fiber preventing constipation is scant...fluid intake does not determine stool bulk or encourage colon transit time, and...there is no proven link between exercise levels and chronic constipation” (p. 848). In conclusion they suggested that nurses refrain from pushing their elderly patients into diet, fluid and exercise regimes that might be of no benefit at all.

Women are more frequently diagnosed with functional gastrointestinal disorders than men and research has explored the possible physiological and psychosocial reasons for these gender differences (Chang et al., 2006). Women have frequently reported feeling dismissed as depressed or hysterical when seeking medical care for ambiguous chronic illness (Johnson & Johnson, 2006). Burton (2003) found that although IBS and other MUPS were often associated with psychiatric morbidity, many MUPS patients demonstrated no definite psychological illness at all and those with severe mental health problems rarely denied them. Evidence also suggests that active persons with IBS who do not seek medical care are psychologically similar to the non-IBS population (Drossman & Swatkowski, 2010). Nevertheless, psychological factors are important in FGIDs because of their potential influence on gut physiology, a person’s experience of symptoms and subsequent illness behavior, their choice of therapeutic approach, and illness outcomes (Drossman et al., 1999).

The Biopsychosocial Model

Staff at the constipation clinic we studied espoused a biopsychosocial model of patient care. The philosophical underpinnings for this approach derived largely from the work of Drossman, who in turn drew on Engel’s (1977) seminal article. Engel, an internist, psychiatrist and

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3 psychoanalyst, was a specialist in FGIDs. He argued that the reductionist biomedical model,
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5 based on the premise that all truly medical problems can be reduced to a clearly defined
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7 biological pathology, makes no room for the psychological and social context of the patient and
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9 therefore overlooks the importance of these factors for the practice of medicine. He proposed the
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11 biopsychosocial model as an alternative scientific model. Engel's model "proposes that illness
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13 and disease result from simultaneously interacting systems at the cellular, tissue, organismal,
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15 interpersonal, and environmental levels" (Drossman, 1998, p. 260).
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20 Another common model in the literature is that of patient-centered care. This emphasizes
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22 respect for the patients' rights, dignity, own life goals and projects (Brody, 1999). Although
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24 different in terms of their emphasis the two models are seen as largely inter-related and
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26 complementary. Drossman and Swatkovski (2010), for example, have argued for patient-
27
28 centered care plans that are biopsychosocial in their approach.
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32 Although the biopsychosocial model has had a significant impact on medicine,
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34 interdisciplinary research and medical teaching, it has neither displaced the biomedical model
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36 nor gone without critique. According to Shorter (2005), one reason why it was not
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38 overwhelmingly adopted was because the model failed to address the overwhelming success of
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40 pharmacotherapy. The success of biological research and pharmacotherapy also laid the
41
42 groundwork for Nassir Ghaemi's (2009) critique of the biopsychosocial model. In his view,
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44 reductionism is not always wrong. He reminded his readers that peptic ulcer disease was thought
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46 to be a psychosomatic illness until a relatively simple bacteria was discovered to be the cause.
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48 He also criticized the biopsychosocial model for not specifying how to prioritize the different
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50 elements, leading to eclecticism in clinical practice.
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Even though a philosophy of illness and disease were clearly laid out by the model, definitions of biopsychosocial practice and treatment were not. Engel (1980) in a later article on the clinical application of the model, rectified this omission somewhat. He agreed, however, that the model remained “a conceptual framework and a way of thinking” and did “not add anything to what is not already involved in patient-care” (1980, p. 543). In the case of FGIDs, Drossman (1998) took the model further and argued in favor of biopsychosocial treatments. He contended “ongoing and future research involving behavioral treatments, including cognitive-behavioral therapy, relaxation, interpersonal psychotherapy, and hypnosis, I believe, will not only prove effective, but also more lasting than pharmacological treatments” (p. 265).

Another criticism of the biopsychosocial model is that notions of the “social” are frequently limited to family issues, interpersonal community relationships or behaviors within some degree of personal control. Bartz’s (1999) article illustrated a compelling example of this. The general practitioner working with Native Americans with diabetes who participated in the study, despite her biopsychosocial philosophy of care, felt compelled to focus on diet and exercise (things she felt she could influence) rather than the “stress” her patients tried to discuss with her. “Stress” in this case was embedded in wider social factors involved in disease-causation and its lived-experience, such as structural violence, poverty and relationships within the healthcare system itself. Healthcare relationships are an important yet often overlooked aspect of the “social” within the biopsychosocial model that is highly relevant to understanding chronic constipation and, we would argue, other poorly understood conditions.

Qualitative Research and Poorly Understood Conditions

In this article, we contribute to a broader qualitative literature on the illness experiences of people who live with ambiguous diagnoses and who have recourse to limited medical therapies.

Chronic pain is particularly represented in this literature. In the case of fibromyalgia, a chronic pain syndrome, the ambiguity of the diagnosis (Madden & Sim, 2006) and the daily lived-experience of chronic pain (Raheim & Haland, 2006) have been explored through in-depth interviews. These studies demonstrate the particular impact these conditions have on individuals and families.

Qualitative researchers have also used phenomenological and narrative approaches to explore endometriosis and chronic pelvic pain. Butt and Chesla (2007) found that nearly all the women in their study “had difficulty getting answers regarding the cause of the pain”, and that “erroneous explanations were frequently offered by health care providers” (p. 574). Even when a diagnosis was forthcoming there were no permanent solutions for the pain. Carter (2002) interviewed children and their families who were affected by chronic pain which health professionals could neither diagnose nor cure, while Guell’s ethnographic work (2007) was with children diagnosed with idiopathic arthritis, a rare disease. Both studies demonstrated that whether or not a diagnosis is available, the children, like adults with similar conditions, lived and coped with an “invisible” illness, one that doctors and biomedical technologies could not see, measure, or treat consistently.

Qualitative researchers in this area aim to shed light on people’s perspectives and expertise to raise awareness among health professionals and the general public and to offer alternative approaches to more effective health care. The current article contributes to this literature by giving voice to some people’s experience of living with chronic constipation, a supposedly “functional” condition. We also, based on ethnographic analysis, demonstrate why critically appraising the category “functional” and understanding illness experience, particularly

past healthcare relationships, are fundamental in explaining why the biopsychosocial model was sometimes challenged in this case.

Methodology

In this study we asked how persons with chronic constipation, referred to a specialist clinic, experienced their illness, health care and their relationships with health care providers. Collaboration with the clinic as research site began in October 2008 and has continued beyond the period of formal field work, which took place over five months between April and September 2009. The first author undertook the fieldwork and analyzed the data. We adopted a narrative-ethnography approach which combines the “epistemological, methodological, procedural, and analytical sensibilities” of both narrative analysis and ethnographic research (Gubrium & Holstein, 2008, p. 251).

Ethnography, as one kind of qualitative inquiry, makes a particular kind of contribution to clinical research by exploring people’s perspectives and experiences and by building trusting relationships which allow for observing, witnessing and participating in the clinic, the community and the home. An ethnographer both listens to what people say and sees what they “do” in multiple contexts. Ethnographic work on diabetes (Ferzacca, 2000; Smith-Morris, 2006), cancer (Sinding, 2010) and anorexia (Warin, 2010) have all shed light on complex realities, home-contexts and obstacles to health care (both ideological and institutional). These kinds of findings emerged through ethnographic fieldwork and are clearly relevant to practitioners and policy-makers.

Recruitment

We recruited 11 patients to participate in this study. The aim was to follow each patient in their trajectory of care over the five months of field work through multiple points of contact. At the

time of this research, it took approximately three to four months for a new patient to see the registrar, undergo tests, and have their first appointment with the consultant. Therefore, to be able to witness this trajectory of care, patients needed to be recruited in the first month. The clinical collaborator (third author) estimated we could feasibly recruit between 10 and 12 patients in this time. Three new patients are seen at the clinic every week, but many more in follow-up, and thus we aimed to recruit equal numbers of both. During the first month, we sent all new patients letters inviting them to participate in the study. The clinic secretary followed up each letter with a phone call asking the patient whether they were willing to be contacted by the first author. We recruited four new patients over the first month in this manner. The first author concurrently attended the clinic during this time. Clinic secretaries handed returning patients flyers introducing the study when they registered for their appointment. Staff handed out information sheets and consent forms to those patients who were interested in participating and the first author was available to speak with patients in person after their appointment. We recruited seven returning patients in this manner.

Methods

The study involved multiple qualitative methods including unstructured, semistructured and informal open-ended interviews, participant-observation and a focus group. Ten patients were interviewed in their homes and one in the workplace. Interviews in homes normally took place in the living room or kitchen which were both comfortable for participants and permeable. Friends, children, partners and mothers sometimes moved through these spaces and often added their voices to the interviews. Interviews lasted between one and three hours and were digitally recorded with participants' consent. The interviews were open-ended and unstructured, aiming to build rapport and to allow participants to tell their stories. The opening question was simply

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“Tell me about your experience with constipation, how it all began and how you’ve come to be a patient at the clinic.”

After the first interview, the first author attended the various clinic appointments patients had over the course of the study, keeping detailed field notes about doctor-patient communication and interaction, the conversations (informal interviews) that took place while waiting for appointments, and the patient’s reflections immediately following them. Emerging themes from the narrative-interviews and observations were explored in greater depth during a focus group in August 2009, which 6 of the 11 patients attended. Finally, toward the end of the study a semi-structured interview was conducted with each patient in their home or workplace.¹ The first author spent time interacting with staff in the hospital informally to gain an insider’s view of the clinic’s operation and the staff’s perspectives and roles. The specialist nurse was also assisted in the conduct of weekly yoga classes during a five-week course for a group of patients at the hospital which included one study participant. Finally, all four staff members were interviewed in July: three at their homes and one in the workplace. In summary, the data on which this article is based consisted of 25 recorded interviews, a 2 hour focus group, and more than 45,000 words of field notes.

Analysis

Data-gathering and analysis occurred concurrently. All first patient-interviews were analyzed systematically with the use of the audio-coding feature of QSR International’s (2008) NVivo 8 qualitative data analysis software. The steps in the analytical process were informed by two similar approaches to narrative analysis; Lieblich, Tuval-Mashiach, and Zilber’s (1998) holistic content perspective and Riessman’s (2008) thematic narrative analysis. Interviews were divided into sound-bites and coded according to topic and were then analyzed for emerging themes

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3 across interviews. Narrative analysis has traditionally been dependent on written transcripts.
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5 Audio-coding, used in this study, represents a novel approach which offers social researchers the
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7 opportunity to engage with their data in new and exciting ways (Wainwright & Russell, 2010).
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9 The findings from these interviews, together with field notes based on participant-observation,
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11 fed into subsequent fieldwork such as the focus group and the semi-structured interviews with
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13 staff and patients.
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17 Accuracy in the representation and interpretation of patients' narratives and stories was
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19 member-checked by providing every participant with a draft of the work in progress which they
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21 could discuss with the first author during the second interview. This exercise was conceptualized
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23 as a way of "giving something back" and participants were enthusiastic about the process. We
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25 perceived the member-checking exercise to be a positive experience for patients who, because of
26
27 the intimate nature of their disease, live with it in relative isolation. Therefore, providing patients
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29 with the text served not only the contested goal of validation (Koro-Ljungberg, 2008) but also
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31 that of collaboration and mutual-learning. In terms of the project's applied goals, the first-author
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33 prepared a report with practical recommendations and feedback for improving the service which
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35 has subsequently been used to change certain practices.
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41 *Ethical Considerations*

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43 The research proposal was thoroughly scrutinized and approved by three different ethics
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45 committees: that of the relevant university department, the hospital ethics board, and the relevant
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47 United Kingdom National Health Service research ethics committee. The key ethical issue we
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49 faced was balancing a collaborative approach with patients and clinic staff with the protection of
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51 personal information elicited in interviews. The intimate nature of the topic and the deeply
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53 personal stories elicited by the first author meant that outsourcing transcription would have been
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inappropriate. Furthermore, because the consultant (third author) was both collaborator and participant in this research, raw interview, focus group and field note data was not shared with him in order to respect the fact that some patients might have told the first author things they would not have told their consultant. Such discrepancies were observed on more than one occasion during clinical consultations. In what follows, all patient names and identifying details have been changed to protect their anonymity.

Findings

Of the 11 patients in this study, 10 were women. Patients’ ages ranged from 20 to 58. Both gender and age distributions were representative of the clinic as a whole. All patients were born and raised in Britain but differed considerably in terms of occupation, socio-economic status, and formal education. The staff involved in the study were the male consultant, a male registrar, a female specialist nurse and the female clinic secretary. In what follows, we look first at the nature of the clinic and the health professional narratives concerning it before going on to look at patients’ lived experience of the disease.

The Research Context and Health Care Professionals’ Perspectives

There are only two clinics in England specializing solely in the treatment of chronic constipation. The clinic we investigated was founded by the consultant in the year 2000. At the time of this research, it was held on Monday mornings in a hospital outpatients department and was treating approximately 450 patients a year. The aim of clinical staff was to take people’s constipation seriously, give people time, legitimize their suffering, relieve them from a sense of blame, and work toward successful management of the illness via laxatives, enemas, some complementary therapies, support, pain killers, innovative treatments when available and, for some, surgical intervention. Interviews with staff at the clinic indicated that it was in a state of rapid evolution

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3 and was guided by a long-term vision. Approaches to care and interventions changed with
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5 clinical experience and as new information based on scientific research in the areas of
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7 physiology, effective clinical practice and new treatments became available.
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10 Most patients arrived at the clinic by referral from either primary or specialist care and
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12 were seen within five weeks. In the first appointment the registrar spent an hour working through
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14 a battery of questions to elicit the illness history. According to him, his role was “to lower
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16 people’s expectations.” Because the disease is poorly understood and few effective treatments
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18 exist, if patients expected to be diagnosed and cured promptly most would be disappointed.
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20 Rather, the focus was on symptom management. Patients had an internal examination and
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22 received prescriptions for various laxatives, stool softeners, or pain medications to try and
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24 improve their symptoms. They were also explained a lot of information including what was
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26 known about constipation and some of the most recent research findings. In the following 2-3
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28 months patients returned to the hospital for tests. The two main tests were the proctogram (to
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30 diagnose a rectocele or muscular abnormalities)² and the transit test (to diagnose slow-transit
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32 constipation).³ During the 15-20 minute second appointment, the consultant discussed test
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34 results, what was known about chronic constipation and appropriate courses of action. He said of
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36 his role “most of what I do is listen.” Some patients were then referred on to the specialist nurse
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38 who offered a range of services including biofeedback, yoga-therapy, relaxation techniques, and
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40 advice on diet and helpful toilet habits. She tailored her approach to the patient and commented
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42 that “some want everything to be very medical and practical” whereas others needed the space
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44 and time to talk and do some relaxation.
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53 Broadly this clinic espoused a biopsychosocial approach to care. However, what emerged
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55 from countless conversations with staff over the course of field work was their uncertainty about
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3 how best to provide this care and the feeling that some patients were not “open” to psycho-social
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5 therapies or to the discussion of the psycho-social aspects of their disease. An ethnographic
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7 example of such a case where the patient appeared to “resist”, “shut-down” or “not be open to”
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9 the biopsychosocial interview of the consultant was recorded in the researcher’s field notes as
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11 follows:
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15 The consultant asked about her parents and whether they were together when she was a
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17 child, she said yes but that they got divorced when she was eleven or twelve. He asked:
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19 “what was that like?” She said: “fine.” He asked: “was there less fighting at home?” She
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21 said: “it didn’t change much.” Her answers were short and void of any detail or emotion.
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23 However, she did rub her eyes a couple times and I wondered whether she was getting
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25 upset by these questions. She seemed fragile to me that day. When they returned to the
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27 topic of her physical condition the awkwardness lifted immediately and she answered
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29 questions in a more engaged fashion
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37 Such awkward silences and tense conversations represent the kind of experiences which have
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39 contributed to the health professionals’ view that some patients are “not open” to a
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41 biopsychosocial approach to their care whether it be in consultation with the doctor or specialist
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43 nurse. During our second interview the participant was reminded of this dialogue and asked:
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46 I: What did you think about being asked those questions?

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48 P: I don’t know it’s just. I just didn’t think that was relevant but, but obviously it is,
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50 because something can go back to your childhood can’t it?
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53 I: Did that upset you to be asked those questions?

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55 P: Nah, hah! No, I just wondered why they were being asked.
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Thus it could be that her “non-openness” had less to do with rejecting a biopsychosocial model and more to do with confusion and, we shall go on to argue, negative past experiences of being “fobbed-off”. This is just one of many themes from patients’ narratives to which we now turn.

Embodied and Social Experience: Pain, Uncertainty, and Self-Esteem

Although three patients described their pain as “uncomfortable” or “intermittent”, for all the others the pain they were either experiencing or had experienced was so severe and disabling that their ability to carry on with their daily lives was impeded. At the first interview Katie described abdominal pain that was so debilitating she had been forced her to take sick-leave from work for many weeks. None of the half-dozen laxatives she was taking worked and the enemas which did work caused her such severe pain that she would miss work to recuperate from them. She explained that she had stopped using an enema once a week because she was too afraid that they would make her ill, miss work, and risk being fired. She had not had a bowel movement in the previous four weeks.

In observations and conversations with the clinic consultant, it became clear that part of his role was to reassure patients that using laxatives regularly was safe and to relieve some of their guilt, fear, and anxiety on that score. Nevertheless, patients still struggled over accepting a dependence on laxatives. They worried about whether they could be harming themselves and how long it would take before they lost their effect. For example, Charles said “well I try not to [use laxatives] because otherwise I’ll get used to it and then I won’t have anything, then I’m going to have real problems aren’t I? So that worries me.” Patients also worried about having a body over which they had little control. Those dependent on laxatives complained that their unpredictable efficacy meant they always needed to be near a toilet because, when they felt the

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urge, it could just “come away” with little warning. Experiences of soiling oneself in public and in front of others were so horrifying and embarrassing that some said they now preferred to stay at home.

The disabling side-effects of constipation could thus lead to home-boundedness, isolation, retreat from the working world, and to consequent feelings of self-worthlessness. Physically, the severe bloating and loss of control over their bowels made many patients feel uncomfortable with their own bodies. Some avoided having a sex life altogether because of abdominal pain and feeling unattractive. Katie said “actually it’s made a big difference in our sexual life, like we don’t, do it, like sexually because I’m so uncomfortable, I’m so uncomfortable with me body. So it’s not that nice on him but I just can’t at the moment.” For some the loss of independence was experienced as a loss of self. Rebecca described herself as a particularly outgoing and sociable person but reflected that during the previous year:

Me life just completely changed. I’ve always been ambitious and had things I wanted to do, and fiercely independent and such and me life to just become, well not a vegetable but, this invalid really who had to rely on other people to help us and look after us really and rely on the state for them to pay for me which fiercely irritates us ‘cause I like to earn me own money and it was like desperation because we thought at one point this is going to be my quality of life, lying on a bed day in day out watching DVDs and reading about stuff.

Rebecca’s commentary on her condition shifts her sense of bodily discomfort from Katie’s relationship with her partner to, in Rebecca’s case, her relationship with the state. In both cases their quality of life has been severely affected.

Prior Experience, Feeling "Fobbed-Off" and Gaining Legitimacy

Six of the eleven patients told stories of family members with histories of severe bowel problems, including deaths by bursting and cancer. Not surprisingly they were troubled by the possibility of an underlying diagnosis being missed. Seven had had constipation for decades if not since childhood, and so for them constipation was an unfortunate "fact of life". Most had attempted to deal with their constipation on their own for many years by self-prescribing laxatives and enemas. Some admitted that the embarrassment of speaking to a physician and fear of a rectal examination had kept them quiet. Eventually their symptoms became so unbearable they were forced to seek medical help. Such prior experience can help us understand why being told "nothing is wrong", "lots of people get constipated" or "sort out the depression first" is unsatisfactory.

Most patients had stories of previous physicians saying: "nothing is wrong", which was experienced as a blatant failure to acknowledge how sick they were. Not surprisingly, they considered this an inadequate response, and in most cases led to them seeking further medical opinions. A number of patients told stories of being referred to gynecologists or sexual health clinics because the abdominal pain was thought to be related to endometriosis or a sexually transmitted disease. Most felt "fobbed-off," an expression meaning dismissed or not taken seriously by health professionals. When tests came back showing "nothing", some said they felt their doctors were putting everything down to depression or mental illness. Some felt blamed and judged by suggestions that they were not eating the right foods and exercising enough. Highly regarded doctors knew them and their history, understood their problem, let them talk, investigated the problem with tests, and referred them to appropriate specialists.

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Referral to the constipation clinic offered a sense of legitimacy. It was the place where patients received more time and thorough investigations than most had ever had before. It was also where they garnered the latest scientific evidence that people like them did have something wrong with their bowel and that their pain was real. Tests demonstrated to some patients that their bowels moved abnormally slowly and neurological images from research projects showed how artificial distention of the bowel caused much more pain activity in the brain of someone with IBS compared to someone without (Coffin, Bouhassira, Sabaté, Barbe, & Jian, 2004). The tremendous relief felt by patients when they finally found someone who believed their pain was real was clear from the participant-observation and came through in most, if not all, interviews.

Suggestions that “it was all in their heads” had frequently come to be accepted as the only explanation and some told stories about how they had seriously begun questioning their sanity. In retrospect, they felt embittered or confused by the fact that their mental state had been questioned or considered causative. Rachel’s constipation-related abdominal pain came on suddenly at the age of twelve. She explained that one particular doctor:

suggested at one point that it was psychosomatic, and I was convinced that it was by that point, it had been quite a lot of months, there was no medical reason apparently but really now when I look back on it they didn’t do that much investigation, they were like “it’s either appendicitis or just pregnant” and they really sort of gave up. They didn’t do very many sort of things to sort of explore what was going on. Yeah, I was convinced that it must be psychosomatic. I came up with all these things that I must be unhappy about and then the next time I went it was just completely dismissed, “Oh, we don’t think that anymore”; it was just always like that.

When she was referred to the constipation clinic it was discovered that she had a large rectocele and, after an operation and a constant supply of laxatives and stool softeners used in combination, at the time of this study she was going to the toilet regularly and was no longer taking pain killers.

The Intersections of Life Events, Emotional Well-Being and the Bowels

Although scientific research suggests that psychological morbidity, life-events such as abuse, personality traits, and other psycho-social variables are related to “functional” diseases (Koloski, Talley, & Boyce 2001; Toner & Akman, 2000), the complexity of those connections are often left uninvestigated and the patients’ interpretations neglected. The present research paid particular attention to how life-events, stress, and mental health were woven into patients’ narratives.

Some participants struggled to understand how their condition could be simultaneously “physical” (expressed as a necessary factor for “legitimacy”) yet influenced by their wider social lives and life-histories. Jacqueline lived with her husband and four children and had been sick for eight years. She said:

I’ve always had ongoing bowel problems from as young as I can remember. But when I had me last child, which is eight in July, which I had very premature, I started taking some laxatives and I ended up having an eating disorder through it in the end. But since I started to try and eat again properly which has been the last two and a half years, that’s when this, these problems have started [not just constipation but severe abdominal pain], that I’ve been really worse and it’s affected me, it’s affected my whole family.

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Six other participants stated that their constipation had been an ongoing problem for years or even since childhood. However, many had not considered it a severe enough problem to visit the doctor until the pain, bloating, and feeling “poorly” (unwell) became overwhelming. Jacqueline was open about her depression and found the medication helpful in lifting her mood. However, she was exasperated by doctors’ claims that she must “sort out” the depression before they could deal with her bowels. Her husband, in a tone connoting all his worry and frustration, said:

What really winds me up is when they veer off the actual problem [the bowels] and then they start going ‘well mental state, go on anti-depressants’ and all this. She hasn’t got a mental problem, it is a physical problem that’s affecting her mentally, you know. It’s bound to, it’s driving her crazy! And she’s been suffering for years, so it’s bound to have a mental effect.

Whereas Jaqueline and her husband considered her mental distress to be a direct outcome of her bowel problems, Christina interpreted the causal pathway differently.

It’s like pain and depression now, all in one, through what’s happened, you know mental health. Well what happened, it started with mental health, first I lost a baby nine years ago, that’s how it started. I got really like depressed. Then a couple of years after that I started feeling pain. I was under [name of hospital], keep giving us scans, x-rays, cameras down, cameras up, couldn’t find nothing!? Was at me doctor’s every other day, “Ah, it’s your depression”, this that and the other, putting it down to that.

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3 She began to think she must be “cracking up” because everyone was saying it was in her head.
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5 She went on to explain that she consulted another doctor for a second opinion and was referred
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7 to the constipation clinic where she said they diagnosed “blockages” of the bowel. A rectocele
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9 was also detected and operated on but things had not improved. Numerous times in the
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11 interview, after explaining these findings, she would say things like “So it can’t all be in my head
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13 can it? Because the blockages are there.” Clearly, interpreting these interconnections was a
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15 complex process.
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19 Charles, on the other hand, was convinced his condition had more to do with “mind” than
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21 anything else, but said no physician had ever opened up that dialogue with him. For many
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23 physicians “functional” implies “psychological” (Drossman, 2005). Most of the female
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25 participants told stories about how mental state, psychology, or traumas were topics broached by
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27 their health care providers. Opinions differed regarding how appropriate this was. Charles was
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29 the only man in our sample, and it might be that gender bias accounts for his different experience
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31 of treatment. Perhaps it is less likely that physicians would bring up or discuss stress, his past or
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33 his psychological state with him. Furthermore, unlike almost every other participant, Charles
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35 evoked the turn of phrase “all in my head” in his narrative without apprehension, suggesting
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37 another interesting gender dimension that further research could explore.
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44 In others’ narratives the pain, which triggered medical care seeking, was said to have
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46 come out of the blue and onset was not connected to any particular event in their lives at that
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48 time, although they did say various things “didn’t help”. Most said that stress made their
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50 condition worse or associated life-events with the worsening of certain symptoms but saw
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52 neither as strictly causative.
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55 Discussion

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Quantitative research on the relationship between chronic constipation and quality of life has shown that health-related quality of life is significantly lowered both intra-culturally (Belsey et al., 2010; Dennison et al., 2005) and cross-culturally (Wald et al., 2007). Whereas quantitative research can highlight important relationships between variables, it is often neither suited to understanding the multiple factors that underlie these relationships, nor their consequences in terms of patients' lived-experience (Chang et al., 2006). Whereas a quantitative approach might ask what characteristics (personality, co-morbidity, service use history) persons suffering from "functional" diseases have in common, a qualitative approach might ask what is common about their social experiences of illness and health care, which might affect well-being and shape behaviors. Such approaches help to explain the reluctance, on the part of some patients, to engage with a biopsychosocial approach to care despite the obvious interconnections their narratives draw between their bodies and their wider-lives.

Qualitative research on the experience of chronic constipation is very limited. Most of the qualitative literature comes from nursing, focuses on IBS in primary care settings or the community, and employs questionnaires, focus groups, or interviews in isolation (Bengtsson, Ohlsson, & Ulander, 2007; Bertram, Kurland, Lydick, Locke, & Yawn, 2001; Casiday, Hungin, Cornford, de Wit, & Blell, 2009a, 2009b; Fletcher, Jamieson, Schneider, & Harry, 2008; Fletcher, Schneider, Van Ravenswaay, & Leon, 2008; Fletcher & Schneider, 2006; Jamieson, Fletcher, & Schneider, 2007). The last four references concern the same eight participants within the same study, reflecting the paucity of qualitative research projects conducted in this area. Hakanson, Sahlberg-Blom, Nyhlin, and Ternstedt's (2009) and Hakanson et al.'s (2010) articles are exceptional in having recruited patients from a specialist (gastroenterology) outpatient service. Similarly to our findings, their participants gained a sense of legitimacy and more

supportive care by being referred to a specialist. Furthermore, their experience of an unreliable body which they distrusted resonates with elements of our participants' narratives. In Casiday et al.'s (2009a) study of IBS patients in primary care in the UK and Netherlands, the experiences of home-boundedness or avoidance of social life, frustration with treatments tried to no effect, fear that symptoms might indicate cancer or something equally sinister, dissatisfaction with being told "nothing's wrong", and feelings of ambivalence about using laxatives, are findings corroborated by our study.

Ware (1992) and Åsbring and Närvänen's (2002) research with people with chronic fatigue syndrome and fibromyalgia, uncovered remarkably similar themes to ours including delegitimization, stigmatization, suffering and contested definitions of illness. Children with chronic pain and their parents told Carter (2002) stories like those of our participants about feeling judged, misbelieved and labeled as difficult or dysfunctional (although among our participants "depressed" or "crazy" were the terms used). They also complained of referral fatigue, and the frustration they felt about being asked the same clinical questions over and over again. Thus the wider literature suggests that a person with chronic constipation is likely to experience their illness and health care encounters in ways very similar to individuals suffering from other diseases which are poorly defined and for which few treatments exist.

The current study contrasts with those mentioned above in that it concerns a group of patients at a clinic specialized in the treatment of chronic constipation who, unlike participants in the IBS literature, are not unified under a particular diagnosis. Our participants tended to be confused or dissatisfied with their diagnoses and identified with one or more of the following terms used at the clinic: constipation, constipation-predominant IBS, intermittent IBS, visceral hypersensitivity, slow-transit constipation and rectocele. Often identification with these labels

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occurred over the course of treatment, reflected in the fact that new patients were less likely to name what they had.

Furthermore, our study was ethnographic and employed participant-observation in conjunction with interviews and focus group work. It provided the opportunity to acquire an in-depth and multifaceted understanding of a rare kind of biomedical, specialist, publicly-funded clinic made up of an interdisciplinary team espousing a biopsychosocial approach to care. By virtue of spending time at the clinic, socializing with staff, attending appointments, and spending time in patients' homes, we contribute a perspective in which patients challenge the biopsychosocial approach as the *sine qua non* of practice. This, we surmise, is because of the issues and experiences patients have had with a disease that is tagged with the biomedical label "functional" and the implications of this label for their experiences of health care. We argue that a biopsychosocial approach towards care for this and similar patient groups must include, understand and address the individual's history of health care relationships as a "social" element fundamental to their illness experience and future care. This requires a critical discussion of "functional" disease.

Drossman (2005) argued that the term "functional" is accompanied by certain assumptions about patients, their mental health, their relationships with health care, and the extent to which psychology underlies their problem. Considering the distress and suffering chronic constipation caused individuals and families in this study, it seems a gross misnomer to call such a condition "functional" at all. Most participants were not functioning at all well. Some could barely eat, walk, or sleep because of the pain. Some missed so much work that they were fired or quit. Others no longer had sexual relationships, even with partners. Fatigue kept them in bed and unpredictability worried them and kept them at home. Although patients are commonly

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3 labeled “functional” in the medical and academic literature, this term was absent in all of the
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5 participants’ narratives. No participant in the second interviews, when asked, had heard of the
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7 term.
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11 Some writers have advocated paying greater attention to the psychological
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13 underpinnings of “functional” diseases and their treatment. Nick Read has argued for this
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15 position in his book *Sick and Tired: Healing the Illnesses Doctors Can’t Cure* (2005). Read has
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17 published more than 500 articles from his biomedical research on gastrointestinal function. In his
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19 practice as a physician he has turned to psychotherapy as the primary treatment for people who
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21 live with illnesses that lack a clear cause or pathology. In his book he argued that psychological
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23 distress and functional illness are strongly associated. While refuting the judgment that it is “all
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25 in the mind” he also disagreed that it is “all in the body”. He contended that chronic stress can
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27 alter the function and structure of the body’s organs, including the brain and considered
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29 functional diseases to be manifestations of the stress and loneliness caused by modern living,
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31 particularly in the West. So although ruling out serious organic diseases is important, for him an
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33 exclusively biomedical approach is flawed and can make patients feel misunderstood. “I have yet
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35 to meet anybody I thought was imagining their symptoms or making them up, but I *have* met
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37 thousands upon thousands of ill people who are struggling desperately to protect themselves
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39 from the potentially mind-shattering effects of unbearable life situations” (Read, 2005, p. 135).
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47 At the other end of the spectrum Simon Overton (2009), who was once diagnosed with
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49 functional paralysis, has argued against the labeling of patients as “functional” because of its
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51 persistent association with words such as “hysterical”, “psychotic”, “psychosomatic”,
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53 “psychological” or simply “not real”, terms which perpetuate a deep injustice with regard to
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55 people’s suffering. For him, “to say that a wheelchair bound patient is suffering ‘functional
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symptoms’ downplays the reality of outward signs, the very real fact that the patient cannot move their legs” (p. 29). Telling someone with such a physical condition that it is “all in the mind” almost inevitably causes a breakdown in the doctor-patient relationship. Rather, doctors should communicate to patients with functional disorders that they have a physical problem which medicine currently does not understand. In Overton’s view, physical problems should be treated physically; invoking psychology is irrelevant and inherently prejudiced. He argued that “patients who become stressed by the diagnostic process are likely to worsen their condition, but this is true of any condition” (p. 87). For him, the answer to people’s suffering lies in biomedical research. His “patient’s eye view” gives a different perspective on the biopsychosocial approach applied to functional disorders.

In our study, while most participants made connections in their narratives between emotions, stress, significant life events, and their experience of their bowels and pain, they did so to differing degrees. A common thread was that pain “got you down” and made you feel depressed and depression made pain worse. Some, whether through their own interpretations or because of suggestions made by health care professionals, believed that better management of their mental health would help lessen the severity of their disease or at least make it easier to live with. However several made the point that, even though their emotional state might interact with their symptom severity, this did not mean their constipation disappeared on emotionally “good” days.

As if reflecting the discord between Overton (2009) and Read (2005) in real life, participants in this study, like Overton, expected answers from medicine and wanted their physical problem treated physically. At the same time, following Read, they wanted physicians to care for them as whole persons. Ultimately this meant expecting doctors to listen to and

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3 understand their perspective before asking personal questions. They also wanted respect for their
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5 own interpretations and ideas about treatment. Jessica, for instance, wanted her mental health
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7 issues and her bowel problems to be treated separately because for her they were separate issues.
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10 Clinic staff considered some patients were open to taking a biopsychosocial approach,
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12 which for them involved discussing broader emotional and social issues, whereas some were not.
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14 Our findings suggest it is unwise to conclude that patients consider psycho-social factors
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16 inherently unimportant or irrelevant. Rather, the intense physicality of their problems and their
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18 prior experiences of feeling “fobbed-off” and blamed has primed them to react negatively and
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20 with suspicion to applications of the biopsychosocial model and has left them determined to have
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22 their physical problem acknowledged and taken seriously. Mention of other things going on in
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24 their life, especially if good rapport has not been established, can raise suspicion and the thought
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26 that perhaps the doctor is not taking them seriously.
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32 Patients were not only outside the discourse on “functional” they were also outside the
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34 discourse on “biopsychosocial”. Patients were unaware they were being seen “in a clinic”; most
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36 thought they were simply referred to a “specialist” or a “consultant”. One recommendation made
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38 to the clinic was to demystify their approach by giving patients a better introduction to the clinic
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40 which would include explaining how they operate according to a biopsychosocial model of care
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42 and why they do so. Once patients are invited into the discussion there is a possibility for them to
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44 help define what a biopsychosocial approach should look like and contribute to a patient-
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46 centered model of care.
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50 The ambivalence among patients to the biopsychosocial approach, despite its enthusiastic
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52 espousal by the health care professionals working in the clinic, reflects a cultural trope in
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54 Western biomedicine. Psycho-social aspects of health still tend to be neglected in diseases that
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are clearly “physical” and curable, whereas psycho-social explanations, particularly with regard to stress and mental illness, are most frequently given for diseases which are poorly understood. Indeed Shorter (2005) stated “that it had been for ‘functional’ illness—thought by some to be psychogenic—that Engel’s approach held its greatest appeal” (p. 9).

Even in this clinic, where care was delivered in a way that patients appreciated, the distinction was still present. For instance Susan, who considered she did not have “chronic” constipation but only occasional episodes, spoke in interview about the stress she was under as the only able-bodied member of her family. She explained in interview how she was too busy to eat regular meals and how it was therefore no wonder she was constipated. Even though questions about family relationships, stress, and mental state were aspects of the biopsychosocial approach adopted by the consultant in almost all the consultations witnessed, such issues were not raised in Susan’s case. The difference between her and the others was that her symptoms were mild and she clearly had a “physical” problem, a rectocele identified by proctogram. We suspect that on identifying a “cause”, the consultant saw no need to explore those other aspects of her life any further with her.

Final Thoughts on the Problematic of Implementing a Biopsychosocial Approach

Examples such as these, of health care professionals approaching some people one way when their illness experience can be pinpointed to a physical pathology and others another way when a physical cause is not so clear, have implications for our understanding of why attempts at a biopsychosocial approach might be dismissed or resisted by patients in some clinical settings. This is particularly important because of the frequent, taken-for-granted assumption that a biopsychosocial approach will unquestionably be welcomed by all patients and the frequent failure to see “experiences of healthcare” as an important “social” factor.

This clinic offered a rare opportunity to explore what happens when a team of health care professionals actually attempt to put theory into practice and change the culture of medicine within their walls. What emerges is a clear example of how medicine reflects society (van der Geest & Finkler, 2004) in that “patients” as members of society are created by and help to recreate the culture of biomedicine which emphasizes the physical basis and curability of disease. As members of this society we have become accustomed to body-focused care. Although medicine is beginning to pay more credence to so-called “mind-body” connections, if it continues to apply these approaches predominantly to poorly understood diseases, patients accustomed to the body-focused care they receive for other medical problems will feel “fobbed-off” and blamed, particularly if their disease remains poorly understood.

In many ways, we can see the persistence of Cartesian mind-body dualism in the tendency to apply biopsychosocial principles to diseases whose physical nature is less clear. However, at the same time, advances in medicine are occurring rapidly and scientific evidence for structural abnormalities and differences in pain pathways (Knowles & Aziz, 2009) are already making the notion of “functional” (without identifiable organic cause) obsolete in the case of chronic constipation. At the same time new treatments are being developed (Ford & Suarez, 2011; Tack, van Outryve, Beyens, Kerstens, & Vandeplasseche, 2009) and it might be that a drug or other intervention will effectively treat chronic constipation and its symptoms in the future. When this occurs, we wonder whether psychological and social aspects of people’s lives will continue to be seen as relevant and important by the health professionals who treat them.

Authors’ Note

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Notes

- 1 It was not possible to reach one participant for the final interview. However, this participant did participate in the focus group.
- 2 A rectocele is a pouch which forms in the rectum and causes feces to get trapped.
- 3 Slow-transit constipation is also called “lazy-bowel”. Constipation thus occurs in part because the bowels move waste along more slowly than normal thus increasing the amount of time between bowel movements.

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Bios

Megan Wainwright, MSc, is a PhD candidate in the Department of Anthropology and a teaching assistant in the School of Medicine and Health at Durham University.

Andrew J. Russell, PhD, is a Senior Lecturer in the Department of Anthropology and the Director of the Community Outreach and Engagement Program at Durham University.

Yan Yiannakou, MD, MRCP, is Honorary Senior Lecturer in Neurogastroenterology and Director of Research and Development at the County Durham and Darlington NHS Foundation Trust.